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# **Informal caregivers' experiences and needs when caring for a relative with heart failure: an interview study**

## **Conflicts of interest**

There are no conflicts of interest.

## **Number of words and tables**

There are 4307 words and two tables in the manuscript.

## **Abstract**

**Background:** Informal caregivers play an important role for persons with heart failure in strengthening medication adherence, encouraging self-care and identifying deterioration in health status. Caring for a relative with heart failure may affect informal caregivers' well-being and cause caregiver burden. **Objective:** To explore informal caregivers' experiences and needs when caring for a relative with heart failure in their homes. **Methods:** The study has a qualitative design with an inductive approach. Interviews were held with 14 informal caregivers. Data were analyzed using qualitative content analysis. **Results:** Two themes emerged: "Living in a changed existence" and "Struggling and sharing with health care". The first theme describes informal caregivers' experiences, needs and ways of moving forward when living in a changed existence with their relative. Informal caregivers were responsible for the functioning of everyday life which challenged earlier established roles and lifestyle. They experienced an ever-present uncertainty related to the relative's impending sudden deterioration and to lack of knowledge about the condition. Incongruence was expressed between their own and their relative's understanding and acceptance of the heart failure condition. They also

expressed being at peace with their relative and managed to restore new strength and motivation to care. The second theme describes informal caregivers' experiences, needs and ways of handling the health care. They felt counted upon but not accounted for as their care was taken for granted while their need to be seen and acknowledged by health care professionals was not met. Informal caregivers experienced an ever-present uncertainty regarding their lack of involvement with health care and not being provided with adequate knowledge. They were not invited to share information with health care professionals and their specific expertise was not requested. Health care professionals had neither provided them with knowledge on heart failure nor with information on support groups in the municipality. Informal caregivers appreciated the contacts with the registered nurses specialized in heart failure. Informal caregivers' own initiatives to participate in meetings were positively received by health care professionals. **Conclusions:** Informal caregivers' daily life involves decisive changes that are experienced as burdensome. They handled their new situations using different strategies in order to preserve a sense of "self" and of "us". Informal caregivers express a need for more involvement with health care professionals which may facilitate informal caregivers' situation and improve the dyadic congruence in the relation with their relative.

## **Keywords**

Heart failure, experiences, informal caregiving, interviews, needs.

## Background

Heart failure (HF) is the single most frequent cause of hospitalization and re-hospitalization for older persons and a large public health problem with high societal costs.<sup>1, 2, 3</sup> Patients often need complex care due to old age, cognitive decline, co-morbidities and polypharmacy.<sup>4</sup> The health care resources for these patients have been reported as not meeting the patients' needs.<sup>5, 6</sup>

The majority of HF care is provided by informal caregivers, thus they are a considerable resource to the health system.<sup>7</sup> They provide support during the often erratic course of HF with periods of stability, interspersed with exacerbations and unpredictable acute hospitalizations.<sup>3, 8, 9</sup> Informal caregivers are also essential in supporting patients in complex medical and self-care behaviors.<sup>7, 10, 11</sup> Research has shown that social support from informal caregivers has a positive impact on the patient's quality of life and also leads to fewer re-hospitalizations.<sup>12, 13, 14</sup>

Although informal caregiving represents an opportunity for increased intimacy and connection, it is associated with significant caregiver burden.<sup>5, 6</sup> Informal caregiving impairs health and well-being of the informal caregivers,<sup>15, 16, 17</sup> especially spouses<sup>18, 19</sup> who are particularly susceptible to depression as a consequence of providing an extensive range of care to their partner.<sup>19</sup> Informal caregiving is also associated with financial losses, particularly for female informal caregivers.<sup>18</sup> Informal caregivers feel that they do not receive sufficient support and recognition from health care professionals<sup>20</sup> and informal caregivers' poor health status has been shown to affect patients' condition and prognosis negatively.<sup>21, 22</sup> As the prevalence of HF and the impaired health and well-being of the patients' informal caregivers will increase,<sup>23</sup> it is clearly time to recognize their critical role in health care.<sup>9, 16, 24</sup>

There is extensive research on the challenges of being an informal caregiver for persons with major chronic illnesses, such as stroke and dementia, but research is limited in the field of HF.<sup>7</sup> Few studies specifically focus on informal caregivers' needs<sup>25</sup> and recommendations to address unmet needs.<sup>26</sup> Therefore, increased attention is needed on informal caregivers' experiences and needs to develop a deeper understanding of potential areas of support.

### *Objective*

To explore informal caregivers' experiences and needs when caring for a relative with heart failure in their homes.

### **Methods**

The study has a qualitative design with an inductive approach using interviews. The study was conducted in the mid-east of Sweden in April - June 2013.

Inclusion criteria were informal caregivers who a) cared for a person living in their own homes and who during the past three months had been hospitalized with heart failure as primary diagnosis, and b) were able to understand and speak the Swedish language and to give informed consent. Exclusion criteria were informal caregivers who a) had dementia, or b) cared for a person with dementia.

Routine telephone patient follow-up were made by registered nurses in the cardiac out-patient clinic at a county hospital, three days after the patient's discharge from the hospital. The registered nurses asked the patients with HF if they agreed to give the name of their informal caregiver and if the first author was allowed to contact them by telephone for an interview. Of

44 patients, 42 approved. The first author then contacted their informal caregivers, described the study and obtained their informed consent. Of the 42 informal caregivers contacted, 14 agreed to participate. They included eight female spouses, three male spouses and three daughters. The spouses co-habited with the patients while the daughters did not. Reasons given for not participating were that they did not have anything useful to contribute, were short of time or experienced ill-health themselves. Median age was 71 years (range 50 – 88 years) and the median duration of informal caregiving was 6.5 years (range 1 month - 20 years). The patients' median age was 79 years (range 68 – 93 years).

In this article patients are henceforth referred to as relatives.

### *Data collection*

The interview location was chosen according to the informal caregiver's preference; eight interviews took place in two different neutral places and six informal caregivers were interviewed in their homes. A semi-structured interview guide (Table 1) was used with open-ended questions with follow-up questions and probes when needed.<sup>27, 28</sup> The interview guide was developed by the authors based on the literature on informal caregiving and HF.<sup>9, 16</sup> The interviews were performed by the first author, lasted 25 - 80 minutes and were audio-taped and transcribed verbatim by the first author. The transcriptions were verified by the co-authors.

### *Data analysis*

Qualitative content analysis<sup>29, 30, 31</sup> was performed using the QSR NVivo<sup>®</sup> software program.<sup>32</sup> Initially, all authors read the interviews several times to get a general sense of the content. Coding, categorization and thematization were done inductively in several stages. First,

meaning units were identified and condensed in the original text material and labeled with codes on a descriptive level. The codes were compared for similarities and differences and sorted into categories. The next phase involved searching for themes representing their latent content. Throughout the analysis, the authors went back and forth between the interviews, codes, categories, sub-themes and themes to validate the results. Each step of the analysis was discussed by the researchers at regular meetings until consensus was achieved.

### *Ethical considerations*

The study was approved by the Regional Ethical Review Board in Uppsala (Dno. 2012/541) and conforms to the principles outlined in the Declaration of Helsinki.<sup>33</sup> The informal caregivers received written and oral information. After the interviews the informal caregivers were assured that, if needed, the first author or a counselor would be available for support.

## **Results**

Two themes and five sub-themes emerged in the analysis process (Table 2). The results are presented by each theme and by underlying sub-themes with interview extracts.

### ***1. Living in a changed existence***

The theme includes three sub-themes and describes informal caregivers' experiences, needs and ways of moving forward when living in a changed existence with their relative.

#### ***1. Challenging established roles and lifestyle***

The informal caregivers' responsibility for ordinary tasks in everyday life challenged established roles in the relationship and was reported as burdensome, leading to weariness and hopelessness but was also perceived as a means for personal growth. They were responsible for



medication regimens and for comforting and reassuring the relative. As the status of HF typically fluctuates from day to day, the informal caregivers had to consider the relative's best interest and health status in relation to all activities.

*... he's more dependent on me now and it's good that I can support and take over heavy tasks because I'm strong. But I think that he feels that it's awful to be so dependent, but he doesn't really admit that. [Female spouse]*

The informal caregivers demanded of themselves to always be available in case of a sudden deterioration of HF, which made travel, full-time work and personal activities outside home impossible. The spousal informal caregivers expressed a nagging feeling of neglecting their family, especially their own grown-up children.

*I can't get involved in anything, neither persons nor activities ... so that's in itself a fairly isolated life. [Female spouse]*

*I've noticed that she is more anxious that I should be reachable at all times ... but it's more emotional, not practical. [Male spouse]*

Most activities together had to be carefully planned as they could not go to places with stairs or slightly uphill. Long-distance travel was unthinkable. They spent less awake time together due to the relative's fatigue. Social life with friends and family had decreased due to fatigue, inability to travel or worry over sudden deterioration.

*You can't invite people home then maybe you have to say no just before. Or else there will be a pressure on him that he can't go to bed although he needs to. [Female spouse]*

## *2. Understanding, handling and accepting the heart failure condition and its consequences*

The informal caregivers worried about their lack of knowledge on how to better handle the HF condition in order to delay deterioration. They also experienced an ever-present uncertainty related to the relative's sudden deterioration in HF. A relative's earlier cardiac arrests in public was described as the worst dread, and led to avoidance of out-door activities either together or the relative on their own. They wanted to be physically present when deterioration occurred. The thought of being absent if there was an emergency raised feelings of remorse. Fear of relatives becoming ill during the night resulted in worrying thoughts at bedtime and disturbed sleep. Worry and uncertainty were also expressed over future financial difficulties and not being able to manage the household. A need for more frequent home care services or moving into an old persons' home was expressed. It was hard for the informal caregivers to witness their relative's gradual deterioration in the absence of good days between relapses. When the informal caregivers no longer believed in their relative's recovery it was difficult for them to be supportive and encouraging but regardless of this they continued to provide support.

*But I do wonder though, will he just get worse and worse, or ... Can it be stopped like this? The heart is not getting better ... but what can you do to make it stay like this and not get worse?* [Female spouse]

*... yes, it's the uncertainty. I call everyday and sometimes she doesn't answer and then of course I'm worried sick. Then I call again, once I called every half hour and no one answered, then I knew something was wrong so I went there. I found her lying on the floor in the bathroom.* [Daughter]

Irritation, sadness and resignation were expressed regarding the incongruence between their

own and their relative's understanding and acceptance of the HF condition. To have HF entailed diffuse pain, fatigue, fear of being alone, feeling downhearted, loss of strength and feelings of inadequacy and discontentment. The informal caregivers observed these symptoms and questioned the relative's lack of acceptance of their HF. The prognosis of HF was not easily discussed with their relative, which created a silent distance and frustration in the relationship. The informal caregivers had to adjust to being on non-speaking terms, keeping their thoughts to themselves or sharing them with friends, unless they set their own terms in the relationship. A physician's frankness regarding the prognosis of the relative's HF had a positive impact on the relationship, forcing the relative to accept more realistic expectations and plans.

*... he felt inadequate, but that was impossible to talk about. So we had a real brawl and I told him "I cannot live like this. You are sick and we know that and we will try to handle that but we don't know where we land. But I am not sick. So you have to realize that I need to go outside the house and do my things". [Female spouse]*

*She gets irritated and angry when she is not able to do things the way she did before. She thinks that life should be as it has always been ... I don't understand that mum cannot be grateful for the life she's had and as it is now, it makes me sad actually. [Daughter]*

*... yes but he doesn't accept that he cannot do what he wants. He would surely love to travel for example, but that is out of the question. I've given up the thought of travelling, so I don't care. But he cannot accept it and that can be annoying when I have already let go of those thoughts. [Female spouse]*

### *3. Preserving a sense of "self" and "us"*

The informal caregivers found ways to restore new strength and move forward with their lives. They got respite from caregiving by being with friends, family, house pets or on their own. To go to a café on their own or have lunch with reassuring friends and family were valuable and carefree moments without having to be in control. It was important not to lose one's friends and the potential isolation was a threat to their own well-being. To exercise or take long walks in the woods in order to stay in good health and to find own time and space were means of preserving one's own identity and avoiding to become too absorbed by caregiving.

*I have to keep up with the things that I enjoy doing ... not to become only a caregiver but to remain the person that I am. So one doesn't fall through and give up on everything that is who one is and only engage oneself in the person who is sick. [Female spouse]*

*I exercise a lot and I think I am in good shape and health, and I have a good life, a good home and with a large social network and some close friends. So there are many positive sides. [Daughter]*

The informal caregivers were grateful for still having their relative by their side. The caring implied an increased closeness and solidarity for one another. It was important that their relative understood that HF also influenced the informal caregiver's life. When their relative appreciated the help and comfort, and did not take it for granted, it helped to restore new strength and motivation for continued caregiving. Informal caregivers expressed having better communication and understanding for one another's situations after their relative fell ill with HF. They also spoke of reciprocity of care in that the informal caregiver and the relative at times took turns in being the caregiver versus the caretaker. The reciprocity helped both parties to understand the other's perspective which increased the will to care.

*We have always spent time together, enjoyed each other's company, helped and supported one another. [Daughter]*

*There is this feeling that we are two, and then you struggle together, as a couple. [Female spouse]*

To have HF in one's life entailed difficulties in visualizing both near and distant future. One way to deal with that was to see the frailty of life and not take life for granted. It was better to learn to take one day at a time, seize the day, accept all that happens and move on instead of thinking too far ahead.

*... she will gradually get worse and the prognosis is that she will live another couple of years. It's difficult to start preparing, perhaps it's better to enjoy the opportunities that we still have. [Male spouse]*

*I'm not concerned of that which may come. I take that when it comes, because I cannot solve the problems that might pop up in a year or half a year, I cannot solve those now and there is no point in brooding about it. [Female spouse]*

## **2. Struggling and sharing with health care**

The theme includes two sub-themes and describes informal caregivers' experiences, needs and ways of handling the health care.

### **1. Lacking involvement and feeling confused**

Taking second place when their relative was the focus for health care was understandable and rational for the informal caregivers. Nonetheless, the informal caregivers expressed a need to

be seen and acknowledged. They had seldom been asked by health care professionals on how they were doing or if they were ok. This matter did not surface until asked about it in the interviews. They stated that in order to be seen and acknowledged they had a responsibility to be explicit on what they wanted or needed from health care professionals. On the other hand, in times of weariness and high caregiver burden, the informal caregivers would have preferred the health care professionals to open up a dialogue on the informal caregivers' need of support.

Informal caregivers had not been invited to share information regarding the relative's symptoms and treatment; neither was their specific expertise requested. Health care professionals failed to provide information and education about the symptoms of HF, its treatment and consequences and did not inform about informal caregiver support groups in the municipality. However, the informal caregivers did not express an interest in meeting with other informal caregivers. Instead they preferred meeting with a registered nurse specialized in heart failure to discuss medical and emotional matters.

The lack of involvement with health care professionals had a negative impact on the relationship between informal caregivers and their relative, due to mutual loss of important information regarding changes in medication regimens, relative's symptoms and well-being. Negative impact also occurred due to the lack of opportunity to talk with health care professionals about the emotional and relational consequences of HF.

*... it was one period where I felt that I cannot take it anymore, that somebody could have seen that the other one is collapsing. That someone asks "but how are you doing, can you manage this?" Well, that has never been the case. [Female spouse]*

*I think it should be like it is for a cancer patient. To them they would never give important*

*information unless the patient has someone with them, and it should be the same with us.*

*Absolutely, because you're influenced so much.* [Female spouse]

Informal caregivers shared bitterness towards health care professionals for not taking their relative's first symptoms into serious consideration despite several visits to the physician. Thus, diagnosis and adequate treatment were delayed which created much unrest and confusion. Other reasons for confusion before diagnosis were misdiagnosis and delay in remittance from primary care to secondary care or when the relative refused to seek help despite having symptoms.

*... he felt that something was wrong, but no one listened. Then he began to wonder*

*"if they say that nothing is wrong, and I feel that it is then I must be imagining or ...".*

*Those were very difficult times indeed, for both of us.* [Female spouse]

## **2. Capturing one's own mandate and feeling confident**

Informal caregivers captured their own mandate through acting as deputies for their relative and claiming their rights of involvement in their relative's health care. They took charge of their relative in seeking emergency care if they considered it was needed. To act as deputies also included filing complaints to The Patients' Advisory Committee concerning maltreatment as well as seeking information about new treatment methods. They would also push their reluctant relative to bring up urgent matters with the physician. Initiatives taken by informal caregivers to participate in meetings with physicians and registered nurses were positively received by health care professionals.

*I go with my husband to the doctor and I let them talk first and then, if I think they have missed something, I talk. I say to my husband "you have to tell the doctor exactly how it is otherwise the doctor thinks everything is ok and you continue to feel like this", like with*

*this awful cough he had which was a side-effect to the medicine. I am not supposed to interfere but when I know and when I have questions ... [Female spouse]*

*I read an article in the local newspaper written by a physician, about adding a third electrode into the pacemaker, so I called my husband's physician and asked if that would be suitable for my husband. So within two-three weeks he had his third electrode and it was a new life. [Female spouse]*

Informal caregivers spoke of how they felt confident despite their difficult circumstances. The direct access to the medical clinic was a source of relief. An open telephone line to the registered nurse specialized in heart failure was appreciated by those who had established such a contact, more time was allotted in each visit to the registered nurse and issues beyond medical ones were discussed. Informal caregivers expressed a need for at least one separate meeting with a registered nurse specialized in heart failure. Other factors increasing confidence were an alarm service at home connected to the municipal home care, extended home care services and technical household devices as well as housing adjustments provided by the municipality.

## **Discussion**

The aim of this study was to explore informal caregivers' experiences and needs when caring for a relative with HF living in their own homes. The results show that informal caregivers had to overcome great challenges as they experienced substantial demands without receiving any support. As "unsung heroes" they neither demanded their rights as informal caregivers in the health care system nor did they pay sufficient attention to their own personal needs.

The results add to the knowledge of caregiver burden, lack of external support, need for information and knowledge and reciprocity of care in informal caregiving to patients with HF.<sup>7</sup>



There is one particular concern in the present study which is of increasing interest within the research area, yet still sparsely discussed. It deals with the informal caregiver and their relative as a dyad, meaning the composite of two individuals who have characteristic patterns of social interactions over time,<sup>35</sup> and the incongruence within this dyad. When the informal caregivers' relatives had not accepted their HF diagnosis and were unwilling to discuss the distress it caused, informal caregivers' frustration and feelings of hopelessness increased. They felt emotionally isolated due to this lack of communication. Even if the informal caregivers eventually stated their own terms in the relationship or forced their relative to seek care, this was not done with a light heart. Dyadic incongruence, meaning the lack of communication or inconsistency in perspectives in HF, has recently been discussed by Retrum, Nowels and Bekelman<sup>36</sup> and Kitko with colleagues.<sup>37</sup> They found that incongruent dyads reported more conflict, psychosocial stress and tension which arose in relation to self-care management, when to seek medical treatment and when planning end of life care. In the present study the informal caregivers were not explicit in their needs in relation to the incongruence but their different strategies in order to preserve a sense of "self" and of "us" may have been ways of overcoming the frustration incongruence caused them. They found time and space for their own well-being, seized the day and enjoyed the, sometimes newly found, closeness and solidarity with their relative. In order to support congruence in the dyad, a raised attentiveness of the dyadic relationship is needed among health care professionals. They need to involve the informal caregivers and be open for discussion on relationship issues or if possible refer to a relationship expert. Further research is also needed on how to measure incongruence and to what degree an improved congruence in the dyad will lead to improved outcomes for informal caregivers and their relatives with HF.<sup>36, 37</sup>

Informal caregivers' experienced an ever-present uncertainty which runs through both themes. It was partly due to the unpredictable trajectory of heart failure and a need for knowledge of HF. The knowledge that they did possess, their own specific expertise about their relative with HF, was not requested by health care. In previous research, uncertainty has been shown to be a substantial threat to sustainable caring as well as own well-being and is related to lack of knowledge and loss of control.<sup>38, 39</sup> In the present study we did not measure informal caregivers' knowledge or perceived control. But since none had been offered any education about HF we can presume that their knowledge was in line with previous research where informal caregivers report little understanding of the HF condition, the aims of treatment and the prognosis.<sup>21, 22</sup> The ever-present uncertainty also stemmed from their explicitly expressed need for involvement in their relative's health care. Lacking this involvement gave rise to feelings of exclusion and had a negative effect on the relationship with their relative. A recent large meta-analysis showed that informal caregivers' involvement in their relative's health care, together with health care professionals, led to significantly better health for both informal caregivers and their relatives over a long period of time.<sup>40</sup> This supports the present study's results, showing the importance of supporting and involving the informal caregivers as both co-recipients and co-providers of care. Health care professionals need to share their knowledge on HF with the informal caregivers and promote their involvement, not only count on their care and leave them with a feeling of not being accounted for. In the present study, the informal caregivers' need for information on where to turn for support also resulted in an ever-present uncertainty as the health care professionals failed to acknowledge this need. Winslow<sup>41</sup> shows that help from the community can unburden informal caregivers and increase their well-being. Strömberg<sup>26</sup> points out that community services for informal caregivers are often under-used since it can be difficult for informal caregivers to seek the help they are entitled to due to lack of knowledge of

the procedures. We therefore suggest that health care professionals offer more information on where and how to receive help and relief in the community.

### *Strengths and Limitations*

A third of the informal caregivers agreed to participate in the study. Two of the three reasons given for non-participation - being short of time and experiencing own ill-health - may indicate a more demanding care situation, thus the study may underestimate the need of support. The third reason - not having anything useful to contribute - may be an expression of how they undervalue their role as informal caregivers or are not aware of their needs. Nevertheless, the sample size was judged to be large enough to provide a variety and depth of experiences, but the drop-outs may have induced a selection bias. The inclusion and exclusion criteria in this study warrant a comment. Informal caregivers with dementia were excluded from the study as they were considered to be unable to provide thoughtful insight into their experiences and needs. Patients with dementia were excluded to avoid co-morbidity as a confounder in regards to the informal caregivers' experiences and needs. Also, only Swedish speaking informal caregivers were included in the study. These criteria thus limit the transferrability of our results to dementia populations and non-Swedish speaking populations.

### **Conclusion and Implications for Practice**

This study provides insights about being an informal caregiver to a relative with HF. Their daily life involves decisive changes that are experienced as burdensome. Informal caregivers handled their new situations using different strategies in order to preserve a sense of "self" and of "us". Informal caregivers express a need for more involvement with health care professionals which may facilitate informal caregivers' situation and improve the dyadic congruence in the relation with their relative. The main implications for practice are an increased understanding

of how HF also affects the informal caregiver. It is essential that health care professionals see and acknowledge the informal caregivers as they felt counted upon but not accounted for.

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TABLE 1. Interview guide

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**Main questions**

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If you look at an ordinary day, both a “good day” and a “bad day”, what does it look like?

In which specific situations has caregiving felt good and in which has it felt less good?

How do you approach and handle your role as an informal caregiver?

How does the informal caregiving affect the relationship with your relative?

How does the informal caregiving affect the relationship with your friends, family, personal interests and work?

Please take your time to reflect on your own needs as an informal caregiver and then tell me about them.

Which needs are met, which are not met and why? How can these unmet needs best be met?

How do you experience your encounters with health care?

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**Follow-up questions and probes for clarification**

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What makes caregiving more difficult and what makes it easier?

What is your driving force and motivation behind caregiving?

How does your present life differ from life before the heart failure?

What are your thoughts of the future?

Which information have you received from health care?

Were you asked about your own well-being by health care?

How can health care help or ease the situation for you as an informal caregiver?

What do you mean?

How did you feel then?

What did you think then?

... or through confirming what had just been said.

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TABLE 2. Sub-themes and themes

Sub-themes	Themes
1. Challenging established roles and lifestyle	
2. Understanding, handling and accepting the heart failure condition and its consequences	1. Living in a changed existence
3. Preserving a sense of "self" and "us"	
1. Lacking involvement and feeling confused	
2. Capturing one's own mandate and feeling confident	2. Struggling and sharing with health care

### What's New?

- Informal caregivers handled their new situations using different strategies in order to preserve a sense of "self" and of "us".
- Increased involvement with health care professionals may facilitate informal caregivers' situation and improve the dyadic congruence in the relation with their relative.
- It is essential that health care professionals see and acknowledge the informal caregivers as they felt counted upon but not accounted for.